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However, it must be emphasized that group probabilities do not necessarily speak to individual cases.

Etiology of Schizophrenia

The cause of schizophrenia has not yet been determined, although research points to the interaction of genetic endowment and major environmental upheaval during development of the brain. This section first discusses genetic studies and then turns to the evidence for neurodevelopmental disruption. These lines of research are beginning to converge: neurodevelopmental disruption may be the result of genetic and/or environmental stressors early in development, leading to subtle alterations in the brain. Furthermore, environmental factors later in development can either exacerbate or ameliorate expression of genetic or neurodevelopmental defects. The overarching message is that the onset and course of schizophrenia are most likely the result of an interaction between genetic and environmental influences.

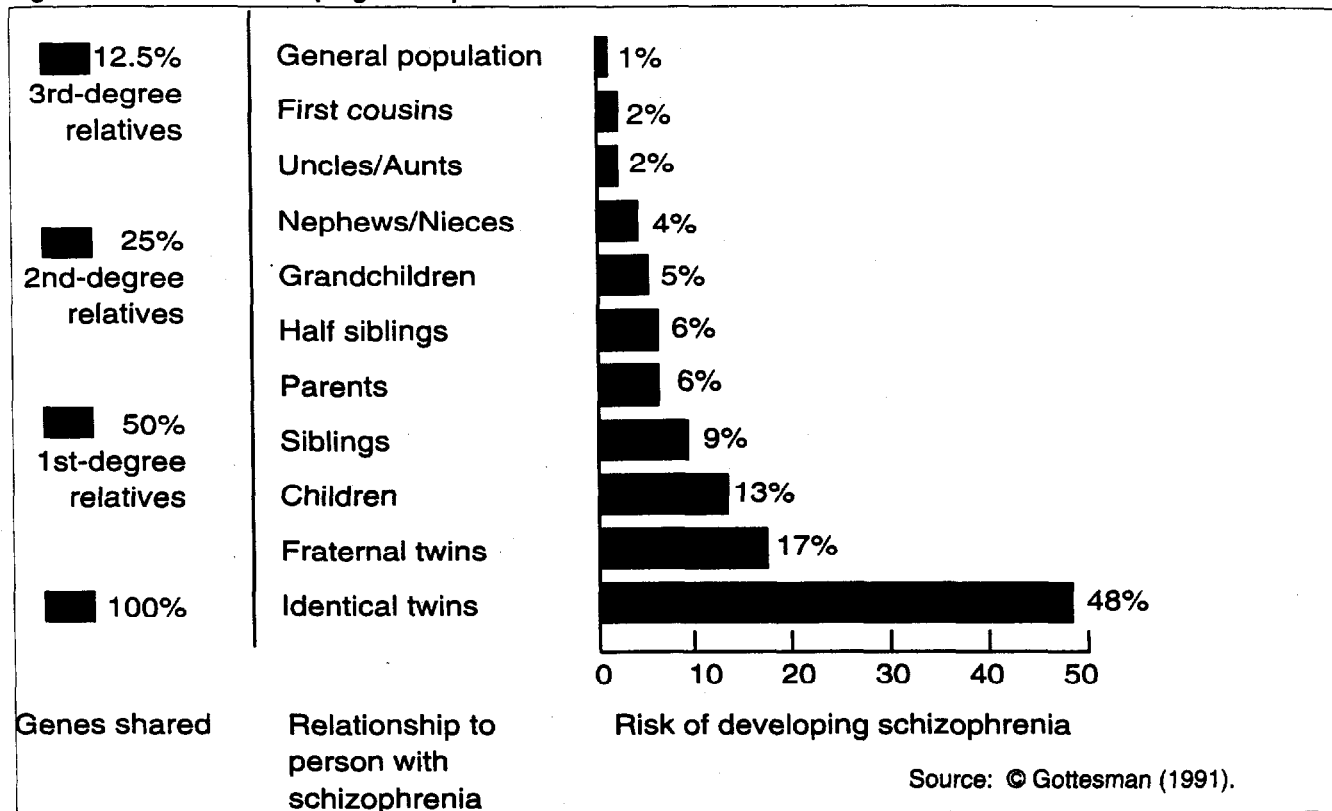
Family, twin, and adoption studies support the role of genetic influences in schizophrenia (Kendler & Diehl, 1993; McGuffin et al., 1995; Portin & Alanen, 1997). Immediate biological relatives of people with schizophrenia have about 10 times greater risk than that of the general population. Given prevalence estimates, this translates into a 5 to 10 percent lifetime risk for first-degree relatives (including children and siblings) and suggests a substantial genetic component to schizophrenia (e.g., Kety, 1987; Tsuang et al., 1991; Cannon et al., 1998). What also bolsters a genetic role are findings that the identical twin of a person with schizophrenia is at greater risk than a sibling or fraternal twin, and that adoptive relatives do not share the increased risk of biological relatives (see Figure 4-3). However, in about 40 percent of identical twins in which one is diagnosed with schizophrenia, the other never meets the diagnostic criteria. The discordance among identical twins clearly indicates that environmental factors likely also play a role (DSM-IV).

Current research proposes that schizophrenia is caused by a genetic vulnerability coupled with environmental and psychosocial stressors, the so-called diathesis-stress model (Zubin & Spring, 1977; Russo et al., 1995; Portin & Alanen, 1997). Family studies suggest that people have varying levels of inherited genetic vulnerability, from very low to very high, to schizophrenia. Whether or not the person develops schizophrenia is partly determined by this vulnerability. At the same time, the development of schizophrenia also depends on the amount and types of stresses the person experiences over time. An analogy can be drawn to diabetes by virtue of both genetic factors (e.g., family history) and behavioral factors (e.g., diet, exercise, stress) that interact to determine whether or not a given person develops diabetes. How the interaction works in schizophrenia is unknown, yet the subject of ongoing research (Murray et al., 1992; Spaulding, 1997; Jones & Cannon, 1998; van Os & Marcelis, 1998).

Despite the evidence for genetic vulnerability to schizophrenia, scientists have not yet identified the genes responsible (Kendler & Diehl, 1993; Levinson et al., 1998). The current consensus is that multiple genes are responsible (Kendler et al., 1996; Kunugi et al., 1996, 1997; Portin & Alanen, 1997; Straub et al., 1998).

Numerous brain abnormalities have been found in schizophrenia. For example, patients often have enlarged cranial ventricles (cavities in the brain that transport cerebrospinal fluid), especially the third ventricle (Weinberger, 1987; Schwarzkopf et al., 1991; Woods & Yurgelun-Todd, 1991; Dykes et al., 1992; Lieberman et al., 1993; DeQuardo et al., 1996), and decreased cerebral size (Schwarzkopf et al., 1991; Ward et al., 1996) compared with control groups. Several studies suggest this may be more common among men (Nopoulos et al., 1997) whose families do not have a history of schizophrenia (Schwarzkopf et al., 1991; Vita et al., 1994). There is also some evidence that at least some people with schizophrenia have unusual cortical laterality, with dysfunction localizing

Figure 4-3. Risk of developing schizophrenia.



to the left hemisphere (Braun et al., 1995). To explain laterality, some have proposed a prenatal injury or insult at the time of left hemisphere development, which normally lags behind that of the right hemisphere (Bracha, 1991).

The anatomical abnormalities found in different parts of the brain tend to correlate with schizophrenia's positive symptoms (Barta et al., 1990; Shenton et al., 1992; Bogerts et al., 1993; Wible et al., 1995) and negative symptoms (Buchanan et al., 1993). Positive symptoms are often linked to temporal lobe dysfunction, as shown by imaging studies that utilize blood flow and glucose metabolism. Such dysfunction possibly is related to abnormal phospholipid metabolism (Fukuzako et al., 1996). Disorganized speech (taken to reflect disorganized thinking) has been associated with abnormalities in brain regions associated with speech regulation (McGuire et al., 1998). Negative and cognitive symptoms, especially those related to volition and planning, are commonly associated with prefrontal lobe dysfunction (Capleton, 1996; Abbruzzese et al., 1997; Mattson et al., 1997).

This is perhaps related to unusual neuronal density (Selemon et al., 1998) and may be more prevalent among patients whose families have a history of schizophrenia than those whose do not (Sautter et al., 1995). However, mapping patients' symptoms with brain regions is complex and variable. Researchers believe that the dysfunctions are present in brain circuitry rather than in one or two localized areas of the brain (Andreasen et al., 1997, 1998; Wiser et al., 1998).

Excessive levels of the neurotransmitter dopamine have long been implicated in schizophrenia, although it is unclear whether the excess is a primary cause of schizophrenia or a result of a more fundamental dysfunction. More recent evidence implicates much greater complexity in the dysregulation of dopamine and other neurotransmitter systems (Grace, 1991, 1992; Olie & Bayle, 1997). Some of this research ties schizophrenia to certain variations in dopamine receptors (Nakamura et al., 1995; Serretti et al., 1998), while other research focuses on the serotonin system (Inayama et al., 1996). However, it must be emphasized that in many cases it is possible that perturbations in

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neurotransmitter systems may result from complications of schizophrenia, or its treatment, rather than from its causes (Csernansky & Grace, 1998).

The "stressors" investigated in schizophrenia research include a wide range of biological, environmental, psychological, and social factors. There is consistent evidence that prenatal stressors are associated with increased risk of the child developing schizophrenia in adulthood, although the mechanisms for these associations are unexplained. Some interesting preliminary research suggests risk factors include maternal prenatal poverty (Cohen, 1993), poor nutrition (Susser & Lin, 1992; Susser et al., 1996, 1998), and depression (Jones et al., 1998). Other stressors are exposure to influenza outbreaks (Mednick et al., 1988; Adams et al., 1993; Rantakallio et al., 1997), war zone exposure (van Os & Selten, 1998), and Rh-factor incompatibility (Hollister, 1996). Their variety suggests other stressors might also be risk factors, under the general rubric of "maternal stress."

As a result of such stresses, newborns of low birth weight and short gestation have been linked to increased risk of later developing schizophrenia (Jones et al., 1998), as have delivery complications (Hultman et al., 1997; Jones & Cannon, 1998) and other early developmental problems (Brixey et al., 1993; Ellenbroek & Cools, 1998; Portin & Alanen, 1998; Preti et al., 1998). Among children, especially infants, viral central nervous system infections may be associated with greater risk (Rantakallio et al., 1997; Iwahashi et al., 1998), thereby explaining links between schizophrenia and being born or raised in crowded conditions (Torrey & Yolken, 1998) or during the flu-prone winter and spring months (Castrogiovanni et al., 1998). However, support for these hypotheses is inconsistent and incomplete (Yolken & Torrey, 1995). In fact, it is possible that prenatal and obstetric complications associated with schizophrenia could reflect already disrupted fetal development, rather than being causal themselves (Lipska & Weinberger, 1997). More generally, across the life span, the chronic stresses of poverty (Cohen, 1993; Saraceno & Barbui, 1997) and some facets of minority social status appear to alter the course of schizophrenia.

Presently, it is unclear whether and how these risks contribute to the diathesis-stress interaction for any one person because specific causes may differ (Onstad et al., 1991; Cardno & Farmer, 1995; Tsuang & Faraone, 1995; Miller, 1996). Although genetic vulnerability is difficult to control, certain other important factors can be addressed with current knowledge. An awareness of stressors that increase the likelihood of genetic vulnerability being actualized supports preventive strategies, such as good prenatal health care and nutrition. Furthermore, since life stresses can exacerbate the course of the illness, access to good quality services and social supports, as well as attention to relapse prevention interventions, can have beneficial effects on longer term outcome (Wiersma et al., 1998).

At the same time, researchers and clinicians are striving to integrate findings concerning both diathesis and stress into models of how schizophrenia develops (Andreasen, 1997b). Not only does brain biology influence behavior and experience, but behavior and experience mold brain biology as well. One promising integrative model is the neurodevelopmental theory of schizophrenia developed by Weinberger and others (Murray & Lewis, 1987; Weinberger, 1987, 1995; Bloom, 1993; Weinberger & Lipska, 1995; Lipska & Weinberger, 1997). It posits that schizophrenia develops from "a subtle defect in cerebral development that disrupts late-maturing, highly evolved neocortical functions, and fully manifests itself years later in adult life" (Lipska & Weinberger, 1997; see also Susser et al., 1998).

The nature of the defect, which has not been identified, may be a product of a pre- or neonatal insult to the brain. Further support for the neurodevelopmental theory comes from abnormalities in brain structure that have long been found in people with schizophrenia. Such findings have been interpreted to reflect abnormal neuronal migration in early development (Jakob & Beckmann, 1986; Arnold et al., 1991; Akbarian et al., 1993; Falkai et al., 1995). Researchers have developed animal models of early neurodevelopmental dysfunctions that manifest in later behavioral and functional deficits (Geyer et al., 1993; Lipska & Weinberger, 1993; Wilkinson et al., 1994;

Table 4-8. Selected treatment recommendations, Schizophrenia Patient Outcomes Research Team

Recommendation 1. Antipsychotic medications, other than clozapine, should be used as the first-line treatment to reduce psychotic symptoms for persons experiencing an acute symptom episode of schizophrenia.

Recommendation 2. The dosage of antipsychotic medication for an acute symptom episode should be in the range of 300–1,000 chlorpromazine (CPZ) equivalents per day for a minimum of 6 weeks. Reasons for dosages outside this range should be justified. The minimum effective dose should be used.

Recommendation 8. Persons who experience acute symptom relief with an antipsychotic medication should continue to receive this medication for at least 1 year subsequent to symptom stabilization to reduce the risk of relapse or worsening of positive symptoms.

Recommendation 9. The maintenance dosage of antipsychotic medication should be in the range of 300–600 CPZ equivalents (oral or depot) per day.

Recommendation 12. Depot antipsychotic maintenance therapy should be strongly considered for persons who have difficulty complying with oral medication or who prefer the depot regimen.

Recommendation 23. Individual and group therapies employing well-specified combinations of support, education, and behavioral and cognitive skills training approaches designed to address the specific deficits of persons with schizophrenia should be offered over time to improve functioning and enhance other target problems, such as medication noncompliance.

Recommendation 24. Patients who have ongoing contact with their families should be offered a family psychosocial intervention that spans at least 9 months and that provides a combination of education about the illness, family support, crisis intervention, and problem-solving skills training. Such interventions should also be offered to nonfamily members.

Recommendation 27. Selected persons with schizophrenia should be offered vocational services.*

Recommendation 29. Systems of care serving persons with schizophrenia who are high users should include ACT and ACM programs.

* Edited

Source: Lehman & Steinwachs, 1998a, 1998b.

Lipska et al., 1995) and are influenced by genetics (de Kloet et al., 1996; Zaharia et al., 1996). As promising as these theories are, the causes and mechanisms of schizophrenia remain unknown. Nonetheless, research has uncovered several types of treatment for schizophrenia that are effective in reducing symptoms and functional impairments.

Interventions

The treatment of schizophrenia has advanced considerably in recent years. A battery of treatments has become available to ameliorate symptoms, to improve quality of life, and to restore productive lives.

Treatment and other service interventions often are linked to the clinical phases of schizophrenia: acute phase, stabilizing phase, stable (or maintenance) phase, and recovery phase. Where possible, this report ties available data to these treatment phases.

Optimal treatment across all phases of treatment includes some form of pharmacotherapy with antipsychotic medication, usually combined with a variety of psychosocial interventions. Psychosocial interventions include supportive psychotherapy, and family psychoeducational interventions, as well as psychosocial and vocational rehabilitation. The treatment of individuals with schizophrenia who are

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high service users should be orchestrated by an interdisciplinary treatment team to ensure continuity of services (i.e., assertive community treatment, which is discussed below). Others may benefit from less intensive forms of case management and various self-help and consumer-operated services, described later. It is also important to assist individuals with schizophrenia in meeting their many related needs, such as for supported housing, transportation, and general medical care. These are among the 30 pivotal treatment recommendations of the Agency for Health Care Policy and Research- and NIMH-sponsored Schizophrenia Patient Outcomes Research Team (PORT), which developed its recommendations on the basis of a comprehensive review of the treatment outcomes literature (Lehman & Steinwachs, 1998a). Table 4-8 contains a distillation of key recommendations.

Although the Schizophrenia PORT study recommendations are grounded in research such as that reviewed in the following paragraphs, it is noteworthy that treatment practices fail to adhere to these recommendations, with conformance generally falling below 50 percent (Lehman & Steinwachs, 1998b). The disturbing gap between knowledge and practice is discussed later in this chapter. Many barriers exist in the transfer of information about treatment and evidence-based practice to clinicians, family members, and service users.

Pharmacotherapy

Pharmacotherapies are the most extensively evaluated intervention for schizophrenia. The conventional or older antipsychotic medications (e.g., chlorpromazine, haloperidol, fluphenazine, molindone) and the more recently developed medications (e.g., clozapine, risperidone, olanzapine, quetiapine, sertindole) are used to reduce the positive symptoms of schizophrenia. The newer medications, often called atypical because they have a different mechanism of action than their predecessors, also appear in preliminary studies to be more effective against negative symptoms, display fewer side effects, and show promise for treating people for whom older medications are ineffective (Ballus, 1997). Their introduction has created more

treatment options for people with schizophrenia and other serious mental illnesses. Although the newer, more broadly effective medications have increased hopes for recovery, they also have resulted in greater treatment complexity for patients and providers alike (Fenton & Kane, 1997).

Conventional antipsychotics have been shown to be highly effective both in treating acute symptom episodes and in long-term maintenance and prevention of relapse (Cole & Davis, 1969; Davis et al., 1989; Kane, 1992). Across many studies, positive symptoms improved in about 70 percent of patients, compared with only 25 percent improvement in placebo groups (Kane, 1989; Kane & Marder, 1993). Their common mechanism of action is by blocking dopamine D₂ receptors, and their therapeutic effects are presumably due to D₂ blockade in the mesolimbic system (Dixon et al., 1995).

For acute symptom episodes, treatment recommendations call for dosages of antipsychotic medication in the range of 300 to 1,000 "chlorpromazine equivalents"¹⁴ per day (Lehman & Steinwachs, 1998b). Among patients discharged from inpatient units whose dosage fell outside of this range, minority patients often are much more likely than Caucasian patients to be on a higher dose (> 1,000 chlorpromazine equivalents) (Lehman & Steinwachs, 1998b). Such dosing patterns run counter to evidence that a higher proportion of minority patients, because of lower rates of drug metabolism, may require lower doses of antipsychotics.

Dosage studies have found that moderate levels (300 to 750 chlorpromazine equivalents daily for acute episodes, 300 to 600 for maintenance, although many people require less than 300) are more effective for positive symptom reduction over the long run than very high ("loading"), intermittent, or very low doses (Donlon et al., 1978, 1980; Neborsky et al., 1981; Baldessarini et al., 1990; Levinson et al., 1990; Van Putten et al., 1990, 1992; Rifkin et al., 1991). Very low

¹⁴ A chlorpromazine equivalent is a measure in milligrams of antipsychotic medication doses indexed to the potency of a standard dosage of chlorpromazine, one of the earliest, most widely used antipsychotic medications.

and intermittent dosing substantially increases the risk of relapse, while rapid loading and very high doses greatly increase adverse effects (Davis et al., 1989), although medication programs must be tailored to individual needs. On conventional neuroleptics, patients experience symptom reduction over the first 5 to 10 weeks of treatment, with more gradual improvement sometimes continuing for more than double that time (Baldessarini et al., 1990). The older medications are occasionally found to reduce some negative symptoms as well, although it is impossible to tell from existing research if this is a primary or secondary effect of reduced positive symptoms (Davis et al., 1989; Cassens et al., 1990).

Apart from their minimal effects on negative symptoms, the greatest problem with conventional neuroleptic medications is their pervasive, uncomfortable, and sometimes disabling and dangerous side effects. The spectrum of side effects is broad (Davis et al., 1989; Casey, 1997), yet the most common and troubling are extrapyramidal effects such as acute dystonia, parkinsonism, and tardive dyskinesia (Chakos et al., 1996; Yuen et al., 1996; Trugman, 1998) and akathisia (Kane, 1985).¹⁵ Side effects are evident in an estimated 40 percent of patients, but pinpointing their prevalence is complicated by the vagaries of diagnosis, length of prescription and observation, and variability across individuals and medications. Rare side effects (seizures, paradoxical exacerbation of psychotic symptoms, neuroleptic malignant syndrome) also can be devastating.

Acute dystonia, parkinsonism, dyskinesias, and akathisia are usually treated by lowering the doses of neuroleptics and/or using adjunctive anticholinergic, antiparkinsonian medications (e.g., benztropine). Because these side effects can be mistaken for core psychotic symptoms, the neuroleptic dose is often increased, rather than decreased, exacerbating the side

effects. Many other side effects such as attention and vigilance problems, sleepiness, blurry vision, dry mouth, and constipation are worse in the initial weeks of treatment and usually taper off as a person adjusts to the medication. However, the discomfort and disability of the initial weeks are intolerably disruptive to some individuals. Dosages can be individualized to minimize side effects while maximizing benefit.

Efficacy data on the newer antipsychotics indicate that they are as efficacious as the older agents at reducing positive symptoms and carry fewer side effects. They also offer important additional advantages for some who have had treatment-resistant schizophrenia (Kane, 1996, 1997; Vanelle, 1997; van Os et al., 1997; Andersson et al., 1998).

The prototype of the newer medications, clozapine, has been found effective for about 30 to 50 percent of treatment-resistant patients (Kane & Marder, 1993; Lieberman et al., 1994; Buchanan, 1995; Kane & McGlashan, 1995; Kane, 1996), as well as for patients who have responded to previous medications. Clozapine also seems to help secondary depression and anxiety, and perhaps the negative symptoms of schizophrenia (Buchanan, 1995). Clozapine not only has a very low incidence of tardive dyskinesia (Barnes & McPhillips, 1998) but may also show some promise as its treatment (Walters et al., 1997). However, the use of clozapine was constrained for many years in the United States because of findings that in about 1 percent of patients it causes a potentially fatal blood condition: agranulocytosis, a loss of white blood cells that fight infection. Because agranulocytosis is reversible if detected early, frequent (weekly) blood monitoring is critical (Lamarque, 1996; Meltzer, 1997). Although effective safeguards exist, use of clozapine tends to be limited to those who are unresponsive to, or cannot tolerate, other antipsychotics. The Veterans' Administration sponsored the largest cost-effectiveness study to date of clozapine, comparing it to haloperidol. Studies by Rosenheck and his collaborators (1997, 1998b, 1999) replicated previous findings that clozapine was more effective than haloperidol in treating positive and negative symptoms and had fewer extrapyramidal side effects. In addition to its direct

¹⁵ Acute dystonia is involuntary muscle spasms resulting in abnormal and usually painful body positions. Parkinsonism is defined by tremors, muscle rigidity, and stuporous appearance. Dyskinesias are involuntary repetitive movements, often of the mouth, face, or hands, and akathisia is painful muscular restlessness requiring the person to move constantly.

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pharmacologic effect, the investigators found that clozapine enhances participation in psychosocial treatments, which augments its overall clinical effectiveness (Rosenheck et al., 1998b). Savings associated with use of clozapine were particularly significant among study participants who had averaged 215 inpatient hospital days in the year prior to the study (Rosenheck et al., 1998b).

Increasing numbers of patients with schizophrenia receive newer agents like risperidone (Smith et al., 1996a; Foster & Goa, 1998), olanzapine (Bymaster et al., 1997), and quetiapine (Wetzel et al., 1995; Gunasekara & Spencer, 1998). They have replaced the older antipsychotics in many cases because they cause fewer side effects at therapeutic levels (Umbricht & Kane, 1995) and do not require clozapine's close monitoring. Their effects on negative schizophrenia symptoms are currently being evaluated and hold some promise, as do their effects on some cognitive dysfunctions (Gallhofer et al., 1996; Green et al., 1997; Kern et al., 1998). Furthermore, current cost analyses find these newer medications at least cost-neutral and sometimes more cost-effective in the long run than older agents, despite being more expensive per pill (Loebel et al., 1998).

Thus, as a whole, there is evidence that the newer antipsychotics are more clinically advantageous than the older ones due to the combination of their effective treatment of positive (and perhaps negative) symptoms, their treatment of ancillary symptoms such as anxiety and depression, and their more favorable side effect profile (Lieberman, 1993, 1996; Fleischhacker & Hummer, 1997; Shore, 1998). Having fewer side effects generally results in better compliance with the medication, although atypical side effects can include sedation, weight gain, sexual dysfunction, and other dose-related discomforts (Casey, 1997; Hasan & Buckley, 1998). Although the newer agents have less adverse impact on fecundity, so that more women with schizophrenia can conceive, there are very little data to address the impact of treatment on pregnancy and lactation. While it is not clear whether the newer medications directly lessen the functional disabilities that usually accompany schizophrenia, they may

improve a person's quality of life (Lehman, 1996) and responsiveness to psychosocial, rehabilitation, and therapeutic interventions (Buckley, 1997). Effectiveness in real-world settings may be substantially lower than efficacy in clinical trials, possibly due to patient heterogeneity, prescribing practices, and noncompliance (Dixon et al., 1995).

Ethnopsychopharmacology

Growing awareness that ethnicity and culture influence patients' response to medications has catapulted to prominence the field of ethnopharmacology. In the past decade, studies have demonstrated that psychiatric medications interact with patient ethnicity in multiple ways, with response to the same medication and dose varying by patient ethnicity (Frackiewicz et al., 1997). For example, due to racial and ethnic variation in pharmacokinetics, Asians and Hispanics with schizophrenia may require lower doses of antipsychotics than Caucasians to achieve the same blood levels (Collazo et al., 1996; Ramirez, 1996; Ruiz et al., 1996). Pharmacokinetics and pharmacodynamics also vary across other ethnic groups.¹⁶ Racial and ethnic variation likely stem from a combination of genetic and psychosocial factors, such as diet and health behaviors (Lin et al., 1995).

At the same time, it is possible that the documented medication differences are the result of underlying biological mechanisms of mental illness related to ethnicity, culture, and gender variations. Additionally, the effects of psychotropic medications may be interpreted differently by culture (Lewis et al., 1980). Although knowledge in these areas is incomplete, it is important to consider cultural patterns in dosing decisions and medication management, as well as risks of side effects and tardive dyskinesia. Furthermore, studies suggest that medication differences among African American people diagnosed with schizophrenia may reflect clinician biases in diagnosis and prescription practices more than differences in

¹⁶ For Caucasian, Hispanic, Asian, African-Americans variations, see Frackiewicz et al., 1997; Chinese-Jann et al., 1992; black, white, Chinese, Mexican American-Lam et al., 1995; Lin et al., 1995).

medication metabolism or health behaviors alone (Frackiewicz et al., 1997).

Psychosocial Treatments

Psychosocial treatments are vital complements to medication for individuals with schizophrenia. They help patients maximize functioning and recovery. The PORT treatment recommendations, as noted earlier, stipulate that patients should receive pharmacotherapy in conjunction with supportive psychotherapy, family treatment, psychosocial rehabilitation and skill development, and vocational rehabilitation (Lehman & Steinwachs, 1998a). In the active phase of illness, medication enables patients to be more receptive to psychosocial treatments. During periods of remission, when maintenance medication is still recommended, psychosocial treatments continue to help patients to improve quality of life. Psychosocial treatments assume even greater importance for patients who do not respond to, cannot tolerate, or refuse to take medications. Several decades ago, psychosocial programs were developed that used little or no medication (Mosher, 1999). For a highly selected group of patients at the beginning of their first acute episode of schizophrenia, these programs were reported effective (Mosher & Menn, 1978). Most patients, however, do not meet the selection criteria employed in this study. Few such programs are currently operating (Mosher, 1999), and treatment with antipsychotic medication is recommended in conjunction with psychosocial treatments (Lehman & Steinwachs, 1998a).

Psychotherapy

Outcomes of individual and group therapies have been studied for people with schizophrenia, although not extensively and not in relation to current managed care practices. Overall, it is clear that individual and group therapies that focus on practical life problems associated with schizophrenia (e.g., life skills training) are superior to psychodynamically oriented therapies (Scott & Dixon, 1995a). Psychodynamically oriented therapies are considered to be potentially harmful; therefore, their use is not recommended (Lehman,

1997). Individual, group, or family therapies that combine support, education, and behavioral and cognitive skills, and that address specific challenges, can help clients cope with their illness and improve their functioning, quality of life, and degree of social integration. However, the optimum length of therapy seems to be longer than that afforded by "brief therapy" (Gunderson et al., 1984; Stanton et al., 1984; Hogarty et al., 1997). Additionally, certain targeted therapeutic interventions may be useful in addressing specific symptoms (Drury et al., 1996; Jensen & Kane, 1996). Certain subgroups of clients appear to find different types of therapy more or less useful than others (Scott & Dixon, 1995a).

Family Interventions

Several professionally operated family intervention programs have been developed to help the family member with severe mental illness (e.g., Hogarty et al., 1987; Cazzullo et al., 1989; Mari & Streiner, 1994; McFarlane, 1997). Randomized trials have been conducted for interventions that educate families about schizophrenia, provide support and crisis intervention, and offer training in effective problem solving and communication. These interventions have strongly and consistently demonstrated their value in preventing or delaying symptom relapse and appear to improve the patient's overall functioning and family well-being (Goldstein et al., 1978; Falloon et al., 1985; Strachan, 1986; Lam, 1991; Tarrier et al., 1994; Goldstein 1995a; Penn & Mueser, 1996). Research has suggested that groups of multiple families are more effective and less expensive than individual family interventions (McFarlane et al., 1995). Incorporating family religious and ethnic background may prove useful in family interventions (Guarnaccia et al., 1992). Family self-help groups are discussed subsequently in this chapter.

Psychosocial Rehabilitation and Skills Development

Psychosocial skills training strives to teach clients verbal and nonverbal interpersonal skills and competencies to live successfully in community settings. Skills or tasks are divided into small, simple behavioral elements that the client then learns,

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practices, and puts together. Currently, there is a growing addition of cognitive skill remediation to rehabilitation programs that have focused on social skills training (Bellack et al., 1989; Bellack & Mueser, 1993; Scott & Dixon, 1995a). As one example of the scope of such programs, the program examined by Liberman and co-workers (1998) focused on four skill areas: medication management, symptom management, recreation for leisure, and basic conversation skills. Each area was addressed through concrete topics, with the basic conversation skills module, for example, consisting of active listening skills, initiating conversations, maintaining conversations, terminating conversations, and putting it all together.

The evolution of psychosocial skills training is important yet incomplete. A review in the mid-1990s concluded that its overall impact on social, cognitive, or vocational functioning is modest, and it remains unclear whether these gains are maintained after the training is over and can be used in real-life situations (Scott & Dixon, 1995a). However, a more recent study found greater independent living skills among clients who had received skills training during a 2-year followup of everyday community functioning (Liberman et al., 1998). Several others agree that skills training is effective for specific behavioral outcomes (Marder et al., 1996; Penn & Mueser, 1996). Specific symptom profiles may also influence how effective skills training is for a given person (Kopelowicz et al., 1997). Furthermore, Medalia and coworkers (1998) report recent success adapting cognitive rehabilitation techniques, originally developed for survivors of serious head injuries, for people with schizophrenia, but long-term effects and generalizability have not been determined. This exemplifies both the progress and the need for further refinement of this intervention (Smith et al., 1996b).

In a recent review article, a team of researchers concluded that the most potent rehabilitation programs (1) establish direct, behavioral goals; (2) are oriented to specific effects on related outcomes; (3) focus on long-term interventions; (4) occur within or close to clients' naturally preferred settings; and (5) combine skills training with an array of social and environmental

supports. They also note that most programs do not contain all of these elements, but most are much improved over previous eras (Mueser et al., 1997b).

There are a host of multi-component psychosocial rehabilitation *services* that combine pharmacologic treatment, independent living and social skills training, psychological support to clients and their families, housing, vocational rehabilitation, social support and network enhancement, and access to leisure activities (World Health Organization [WHO], 1997). These are discussed in the later section on service delivery.

Coping and Self-Monitoring

An important goal of recovery and the consumer movement is to enable patients themselves to participate more actively in their own treatment. While complete remission of all symptoms is unlikely for the majority, most can and do learn skills and techniques over time that they can use to manage distressing symptoms and the effects of the illness. Often, better skills in coping and monitoring one's own health status occurs simply through experience. However, the growth of self-help and the development of recovery models for serious mental illnesses has spawned interventions that purposefully teach and encourage active coping on the part of clients and their families. Controlled research is sparse (Penn & Mueser, 1996), except in the area of relapse prevention.

For example, some people find it very useful to pay attention to their own warning signs of relapse or symptom exacerbation, so that additional coping practices, supports, or interventions can be put into place. Norman and Malla (1995) conclude that there is not a standardized set of signs that predict relapse, but that some individuals have and get to know their own reasonably consistent patterns. Herz and Lambert (1995) agree that many people experience predictable signs, although whether a relapse occurs depends on many factors besides the signs themselves. Therefore, the risk and magnitude of relapse can be reduced by monitoring early symptoms and intervening when they emerge (Herz & Lambert, 1995). Watching for such signs is recommended for consumers, family members, and clinicians (Jorgensen, 1998). Specific training

programs for teaching individuals with schizophrenia to identify the warning signs of relapse and to develop relapse prevention plans have been shown to be effective (Lieberman et al., 1998).

Vocational Rehabilitation

Unemployment is pervasive among people with serious and persistent mental illness. Employment is valued highly by the general public and by people with schizophrenia alike because it generates financial independence, social status, contact with other people, structured time and goals, and opportunities for personal achievement and community contribution (Mowbray et al., 1997). These attributes of employment, combined with the self-esteem and personal purpose that it engenders, make vocational rehabilitation a prominent facet of treatment for serious mental illnesses. Vocational rehabilitation is especially important because early adult onset often disrupts education and employment history.

Controlled studies of vocational rehabilitation interventions have shown mixed results (Lehman, 1995, 1998; Cook & Jonikas, 1996). Although such programs do seem to increase work-related activities while people are engaged in them, the gains do not seem to be translated into more *independent* employment once services cease. This has led to the conclusion that ongoing support is needed for many individuals with schizophrenia who wish to work in competitive employment (Wehman, 1988). Recent controlled studies have shown the effectiveness of this newer type of so-called supported employment models, which emphasize rapid placement in a real job setting and strong support from a job coach to learn, adapt, and maintain the position (Drake et al., 1994, 1996; Bond et al., 1997). These models, which are growing in use, strike a dynamic balance between being supportive yet challenging in order to avoid clients' dependency and maximize their growth (Mowbray et al., 1997).

As vocational rehabilitation has moved away from sheltered workshops and toward supported employment models, the Americans With Disabilities Act of 1990 has helped to open jobs and educate employers about reasonable accommodations for people with psychiatric

disabilities (Mechanic, 1998; Scheid, 1998). Additionally, innovations like client-run and client-owned vocational programs and independent businesses have begun to be developed on a larger scale (Rowland et al., 1993; Miller & Miller, 1997). These innovations are part of a larger movement of consumer involvement in the provision of services for people with mental illness (see Chapter 2).

Service Delivery

The organization of services for adults with severe mental disorders is the linchpin of effective treatment. Since many mental disorders are best treated by a constellation of medical and psychosocial services, it is not just the services in isolation, but the delivery system as a whole, that dictates the outcome of treatment (Goldman, 1998b). Access to a delivery system is critical for individuals with severe mental illness not only for treatment of symptoms but also to achieve a measure of community participation.

Among the fundamental elements of effective service delivery are integrated community-based services, continuity of providers and treatments, and culturally sensitive and high-quality, empowering services (Mowbray et al., 1997; Lehman & Steinwachs, 1998a). Effective service delivery also requires support from the social welfare system in the form of housing, job opportunities, welfare, and transportation (Goldman, 1998a), issues that are discussed in the final section of this chapter.

What models of service delivery are most effective? This section strives to answer this question by focusing on models of service delivery for individuals with severe and persistent mental disorders, including severe depression and bipolar disorder, as well as schizophrenia. Although adults with mental illness in midlife confront many service delivery issues—for example, the problem of proper identification and treatment of depression in primary care settings—those who are most disabled by mental disorders encounter special service delivery problems. The focus on the most disabled is warranted for three reasons: (1) Society has a special obligation to those who are most impaired and consequently are the “least

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well off" (Callahan, 1999; Goldman, 1999; Rosenheck, 1999); (2) the body of research on mental health services delivery for this population is extensive; and (3) existing service systems are seriously deficient.

The deficiency of existing service systems is best documented for individuals with schizophrenia. The *majority* of people with schizophrenia do not receive the treatment and support they need, according to a groundbreaking finding of PORT (Lehman & Steinwachs, 1998a). PORT, as noted earlier, developed a series of basic treatment recommendations after reviewing hundreds of outcome studies. It proceeded to determine whether these recommendations were being met by examining current patterns of care in two states in the United States.

Among those with severe mental disorders, any number of special populations might have been the focus for this section. These special populations have severe mental disorders and HIV/AIDS (Cournos & McKinnon, 1997); are involved in the criminal justice system (Abram & Teplin, 1991; CMHS, 1995; Lamb & Weinberger, 1998); or have somatic health problems (Berren et al., 1994; Felker et al., 1996; Brown, 1997). Although some of what follows may be relevant to the unique needs of each of these groups, the evidence base is less well developed.

The remainder of this section focuses on case management, assertive community treatment, psychosocial rehabilitation services, inpatient hospitalization and community alternatives for crisis care, and combined treatment for people with the dual diagnosis of substance abuse and severe mental illness.

Case Management

The purpose of case management is to coordinate service delivery and to ensure continuity and integration of services. Case managers engage in a variety of activities, ranging from simple roles in locating services to more intensive roles in rehabilitation and clinical care. The less intensive models of case management seem to increase clients' links to, and use of, other mental health services at relatively modest cost. More intensive models also appear to help clients to increase daily-task functioning,

residential stability, and independence, and to reduce their hospitalizations (Borland et al., 1989; Mueser et al., 1998a). Overall, models that focus on specific outcomes are more effective than those with global, vaguely defined goals (Attkisson et al., 1992).

More programs are beginning to employ mental health consumers as case managers in their multidisciplinary staff. Results have been positive, but the programs are challenging to implement and require ongoing supervision as do all case management programs (Mowbray et al., 1996). In a controlled study, clients served by case management teams, along with consumers as peer-specialists, displayed greater gains in several areas of quality of life and greater reductions in major life problems, as compared with two comparison groups of clients served by case management teams without peer-specialists (Felton et al., 1995). One randomized clinical trial compared case management teams wholly staffed by consumers versus case management teams staffed by nonconsumers. The study (at 1-year and 2-year followup) found that clients improved equally well with consumer and nonconsumer case managers (Solomon & Draine, 1995). In this series of studies, the case management teams were part of an intensive program of services known as assertive community treatment.

Assertive Community Treatment

Assertive community treatment is an intensive approach to the treatment of people with serious mental illnesses that relies on provision of a comprehensive array of services in the community. The model originated in the late 1970s with the Program of Assertive Community Treatment in Madison, Wisconsin (Stein & Test, 1980). Fueled by deinstitutionalization and the vital need for community-based services, a multidisciplinary team serving psychiatric inpatients adapted its role to patients in the community. For this reason, assertive community treatment often is likened to a "hospital without walls."

The hallmark of assertive community treatment is an interdisciplinary team of usually 10 to 12 professionals, including case managers, a psychiatrist, several nurses and social workers, vocational

specialists, and more recently includes substance abuse treatment specialists and peer specialists. Assertive community treatment also possesses these features: coverage 24 hours, 7 days per week; comprehensive treatment planning; ongoing responsibility; staff continuity; and small caseloads, most commonly with 1 staff member for every 10 clients (Scott & Dixon, 1995b). Because of the intensity of services, assertive community treatment is most cost-effective when targeted to individuals with the greatest service need, particularly those with a history of multiple hospitalizations (Scott & Dixon, 1995b; Lehman & Steinwachs et al., 1998a).

Randomized controlled trials have demonstrated that assertive community treatment and similar models of intensive case management substantially reduce inpatient service use, promote continuity of outpatient care, and increase community tenure and residence stability for people with serious mental illnesses (Stein & Test, 1980; Bond et al., 1995; Lehman, 1998; Mueser et al., 1998a). Among the beneficiaries are homeless individuals and those with substance abuse problems and mental disorders. Evidence of effectiveness is weaker for other outcomes (e.g., social integration, employment) and for amelioration of substance abuse problems associated with schizophrenia, particularly when combined treatment is not offered (Mueser et al., 1998b). Assertive community treatment models are generally popular with clients (Stein & Test, 1980) and family members (Flynn, 1998). There also are some preliminary results suggesting that employing peer (i.e., consumer) or family outreach workers on the multidisciplinary assertive community treatment teams increases positive outcomes (Dixon et al., 1997, 1998) and creates more positive attitudes among team members toward people with mental illnesses.

Psychosocial Rehabilitation Services

As noted above, there are a range of multicomponent programs called psychosocial rehabilitation services that are distinct from the single component skills training interventions described in the section on interventions for schizophrenia. These psychosocial

rehabilitation programs combine pharmacologic treatment, independent living and social skills training, psychological support to clients and their families, housing, vocational rehabilitation, social support and network enhancement, and access to leisure activities (WHO, 1997). Randomized clinical trials have shown that psychosocial rehabilitation recipients experience fewer and shorter hospitalizations than comparison groups in traditional outpatient treatment (Dincin & Witheridge, 1982; Bell & Ryan, 1984). In addition, recipients are more likely to be employed (Bond & Dincin, 1986). Cook & Jonikas (1996) review the outcomes of a wide range of psychosocial rehabilitation programs, including Fairweather lodges (Fairweather et al., 1969) and psychosocial clubhouses (Dincin, 1975), some of which were demonstrated as effective 20 and 30 years ago but have not been widely implemented.

Inpatient Hospitalization and Community Alternatives for Crisis Care

The role of psychiatric hospitalization has changed greatly over recent decades, stemming from the recognition of poor and occasionally abusive conditions, excessive patient dependency, and patients' loss of connection to the community (Wing, 1962; Gruenberg, 1974). More recent evolution in hospitalization traces to changes in the financing of care and the introduction of new medications (Appleby et al., 1993; Bezold et al., 1996). Community-based alternatives for crisis care services began to flourish in lieu of hospitalization (Fenton et al., 1998; Mosher, 1999).

The new priorities of psychiatric hospitalization focus on ameliorating the risk of danger to self or others in those circumstances in which dangerous behavior is associated with mental disorder, and the rapid return of patients to the community (Sederer & Dickey, 1995). Inpatient units are seen as short-term intensive settings to contain and resolve crises that cannot be resolved in the community. For this reason, inpatients are commonly suicidal, homicidal, or decompensating (experiencing the rapid return of severe symptoms) to the degree that they cannot care for themselves or respond to community-based

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services. Inpatient services therefore emphasize safety measures, crisis intervention, acute medication and re-evaluation of ongoing medications, and (re)establishing the client's links to other supports and services (Sederer & Dickey, 1997).

Mobile crisis services have developed in many urban areas to prevent hospitalization (Zealberg, 1997), as have day hospital programs. With crisis services, a multidisciplinary team comes directly to the aid of the client in the community to provide immediate evaluation and services. This new conceptualization of inpatient care and crisis intervention services minimizes the use of hospital resources; however, well-coordinated teams, sufficient community programs, and ready linkages are not widely available, particularly in rural and frontier areas.

African Americans and Native Americans are overrepresented in psychiatric inpatient units in relation to their representation in the population (Snowden & Cheung, 1990; Snowden, in press). Overrepresentation is found in hospitals of all types except private psychiatric hospitals. The reasons for this disparity, while not completely understood, may reflect a mix of limited access to outpatient services and differences in cultural patterns of help-seeking behavior and overt discriminatory practices. Cost, disinclination to seek help, and lack of community support may contribute to patients' delay in seeking treatment until symptoms are severe enough to warrant inpatient care. Clinician bias may also be at work. Cultural differences in treatment seeking and treatment utilization are discussed in greater detail in Chapter 2.

Services for Substance Abuse and Severe Mental Illness

As many as *half* of people with serious mental illnesses develop alcohol or other drug abuse problems at some point in their lives (Mueser et al., 1990; Regier et al., 1993, Drake & Osher, 1997). Theories to explain comorbidity (also known as dual diagnosis) range from genetic to psychosocial, but empirical support for any one theory is inconclusive (Kosten & Ziedonis, 1997; Mueser et al., 1998b). In short, the cause of such widespread comorbidity is unknown.

Comorbidity worsens clinical course and outcomes for individuals with mental disorders. It is associated with symptom exacerbation, treatment noncompliance, more frequent hospitalization, greater depression and likelihood of suicide, incarceration, family friction, and high services, use, and cost (Bartels et al., 1995; Mueser et al., 1997a; Bellack & Gearon, 1998; Havassy & Arns, 1998). Furthermore, patients may be jeopardized by the consequences of substance abuse, namely, increased risk of violence, HIV infection, and alcohol-related disorders (IOM, 1995).

In light of the extent of mental disorder and substance abuse comorbidity, substance abuse treatment is a critical element of treatment for people with mental disorders. Likewise, treatment of symptoms and signs of mental disorders is a critical element of recovery from substance abuse. Yet decades of treating comorbidity through separate mental health and substance abuse service systems proved ineffective (Ridgely et al., 1990; Mueser et al., 1997a).

Research amassed over the past 10 years supports a shift to treatment that combines interventions directed simultaneously to both conditions—that is, severe mental illness and substance abuse—by the same group of providers (Kosten & Ziedonis, 1997; for an example, see Mowbray et al. 1995), but access to such treatment remains limited. Most successful models of combined treatment include case management, group interventions (such as persuasion groups and social skills training), and assertive outreach to bring people into treatment (Mueser et al., 1997a). They typically take into account the cognitive and motivational deficits that characterize serious mental illnesses (Bellack & Gearon, 1998), although many providers still need to be educated (Kirchner et al., 1998). Combined treatment is effective at engaging people with both diagnoses in outpatient services, maintaining continuity and consistency of care, reducing hospitalization, and decreasing substance abuse, while at the same time improving social functioning (Miner et al., 1997; Mueser et al., 1997a).

Although there is little evidence for any particular approach to combining treatments for comorbidity (Ley et al., 1999), recent research suggests that services

incorporating behavioral (motivational) approaches to substance abuse treatment are superior to traditional 12-step approaches (e.g., Alcoholics Anonymous) with this population of clients (Drake et al., 1998). This may be because the more structured behavioral methods better accommodate the cognitive difficulties that accompany schizophrenia. Others, however, find self-help interventions tailored to dual-diagnosis clients quite useful (Vogel et al., 1998). Current research also is seeking to tailor combined treatment to the needs and preferences of specific patient subgroups, such as men, women (Alexander, 1996), people with addiction to multiple substances (as opposed to alcohol addiction alone), and people with histories of physical and psychological trauma (Mueser et al., 1997a).

Other Services And Supports

Comprehensive care for adults with severe and persistent mental disorders also includes ancillary services to deal with such social consequences as family disruption and loss of employment and housing. Ancillary services are those above and beyond symptom management and rehabilitation. They include consumer self-help and advocacy, consumer-operated programs, family self-help and advocacy, and human services. The chapter concludes with a brief review of evidence about integrating the mental health service system and the human services system of which it is part.

A driving force for many of these services is to redress the stigma associated with severe and persistent mental illness. Stereotypes and ignorance are omnipresent (Robert Wood Johnson Foundation, 1990; Wahl et al., 1995). They lead many people to avoid living, socializing, or working with, renting to, or employing people with severe mental disorders (Levey et al., 1995). Stigma reduces consumers' access to resources and opportunities (e.g., housing, jobs), fuels isolation and hopelessness, and leads to outright discrimination and abuse. Thus, overcoming stigma represents yet another challenge of coping with severe and persistent mental illness and of working toward recovery (Wahl & Harman, 1989; Reidy, 1993).

Consumer Self-Help

Self-help groups are geared for mutual support, information, and growth. Self-help is based on the premise that people with a shared condition who come together can help themselves and each other to cope, with the two-way interaction of giving and receiving help considered advantageous. Self-help groups are peer led rather than professionally led.

Organized self-help has a long history, with an estimated 2 to 3 percent of the general population involved in some self-help group at any one time (Borkman, 1991, 1997). Over the past several decades, people with serious mental illnesses have formed mutual assistance organizations to aid each other and to combat stigma. These range from small groups held in a member's home to freestanding nonprofit organizations with paid staff and a range of programs. In general, however, the self-help empowerment trend does not appear to have reached the African-American, Native American, Hispanic/Latino, and Asian-American populations.

As the number and variety of self-help groups has grown, so too has social science research on their benefits (Borkman, 1991). In general, participation in self-help groups has been found to lessen feelings of isolation, increase practical knowledge, and sustain coping efforts (Powell, 1994; Kurtz, 1997). Similarly, for people with schizophrenia or other mental illnesses, participation in self-help groups increases knowledge and enhances coping (Borkman, 1997; Trainor et al., 1997). Various orientations include replacing self-defeating thoughts and actions with wellness-promoting activities (Murray, 1996), improved vocational involvement (Kaufmann, 1995), social support and shared problem solving (Mowbray & Tan, 1993), and crisis respite (Mead, 1997). Such orientations are thought to contribute greatly to increased coping, empowerment, and realistic hope for the future. Additionally, some groups are tailored to meet the needs of consumers who are members of sexual minority groups, men, or those who have also have substance disorders (Noordsy et al., 1996; Vogel et al., 1998).

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A number of controlled studies have demonstrated benefits for consumers participating in self-help. One study of the self-help group Recovery, Inc., found that leaders and members who were surveyed retrospectively reported fewer symptoms and fewer hospitalizations after joining the group than before. It also found the leaders' reports of their psychological well-being to have been comparable to community controls (Galanter, 1988). In another study of 115 former mental patients, Luke (1989) found that those who continued to attend self-help meetings at least once per month over a period of 10 months were more likely to show improvement on psychological, interpersonal, or community adjustment measures than those who attended less frequently. Through a case study, which included focus groups and interviews, Lieberman and colleagues (1991) found a consumer-run support group to improve members' self-confidence and self-esteem and to lead to fewer hospitalizations.

In a survey of mental health self-help group leaders in New York State, respondents identified three positive outcomes that were directly related to their self-help group membership: greater self-esteem, more hopefulness about the future, and a greater sense of well-being. According to survey respondents, all of these positive changes led to fewer hospitalizations (Carpinello & Knight, 1993). A study of six self-help programs in several parts of the United States also reported on consumers' perceptions of self-help programs (Chamberlin & Rogers, 1990). Although not nationally representative, consumers in this study expressed satisfaction with their self-help program, at which they spent an average of 15 hours per week. They reported that their participation helped them to solve problems and feel more in control of their lives.

Consumer-Operated Programs

Propelled by the growing consumer movement, consumer self-help extends beyond self-help groups. It also encompasses consumer-operated programs, such as drop-in centers, case management programs, outreach programs, businesses, employment and housing programs, and crisis services, among others (Long & Van Tosh, 1988; National Resource Center on

Homelessness and Mental Illness, 1989; Van Tosh & del Vecchio, in press). Drop-in centers are places for obtaining social support and assistance with problems, without professionals in attendance. The rationale for consumer roles in service delivery is that consumer staff, clients, and the mental health system can benefit. Consumer staff are thought to gain meaningful work, to serve as role models for clients, and to enhance the sensitivity of the service system to the needs of people with mental disorders. Clients are thought to gain from being served by staff who are more empathic and more capable of engaging them in mental health services (Mowbray et al., 1996).

An appreciation for the potential value of peer support stimulated the Community Support Program of the National Institute of Mental Health to fund local consumer-operated Services Demonstration Projects from 1988 to 1991. These demonstration projects also resulted in the increasing involvement of mental health consumers in the development and provision of peer support, involvement in traditional service roles, evaluation of services, and advocacy. A variety of consumer-operated programs were developed, staffed, and evaluated as states began to fund locally based initiatives (Nikkel et al., 1992; Kaufmann et al., 1993; Mowbray & Tan, 1993). Most evaluations of drop-in centers were in the form of process evaluations that generally found consumers to be satisfied or that programs met their objectives (Kaufmann et al., 1993; Mowbray & Tan, 1993). In 1998, the Federal Center for Mental Health Services initiated a multisite evaluation study of consumer-operated services across the United States (see <http://www.cstprogram.edu>).

In addition to ongoing evaluations, there are several published studies of client outcomes with consumer-run programs, although the research base is modest. Several studies, noted earlier, found improved outcomes with consumer self-help programs. Another study evaluated a consumer-run case management program. It compared the effectiveness of a case management program staffed by consumers with a similar program staffed by nonconsumers. Case managers in both programs, which were part of assertive community treatment, performed brokering, assistance, and support functions, rather than

clinical management and treatment. The randomized trial found that clients assigned to either case management program fared equally well in clinical, social, and quality of life outcomes (Solomon & Draine, 1995). Recently, peer specialists were added to the recommended staffing for assertive community treatment teams; peer specialists provide expertise and consultation to the entire treatment team (Allness & Knoedler, 1999).

Consumers also may be employed as staff in more traditional mental health services operated by nonconsumer professionals. Consumer positions most commonly include peer counselors, peer job coaches, case managers, staff for drop-in centers, outreach workers, and housing assistants. In a survey of 400 agencies offering supported housing to people with severe mental illness, 38 percent employed mental health consumers as paid staff (Besio & Mahler, 1993). As noted previously, consumers in the role of peer-specialists integrated into case management teams led to improved patient outcomes (Felton et al., 1995).

Consumer Advocacy

The mental health field has witnessed great changes in policy development, with consumers playing increasingly visible roles in advocacy. Consumer contribution to policy was initially encouraged by Federal laws mandating consumer participation in planning, oversight, and advocacy activities at the state level (Chamberlin & Rogers, 1990; Van Tosh & del Vecchio, in press). With the establishment of state mental health planning councils and local mental health advisory boards and committees, consumers increasingly have become equal partners in a process often reserved for seasoned policymakers. In addition, consumers have become active participants in the process to reform health and mental health care financing. For example, the Managed Care Consortium was formed in 1995 to create educational opportunities for a host of advocacy organizations across the United States. With funding support from the federal Center for Mental Health Services, this consortium encouraged teams to form in each state to influence the design of managed care programs. Consumers also have entered

the halls of many public sector bureaucracies, serving in leadership roles in Offices of Consumer Affairs and interfacing with other government departments. In what was once believed to be the last bastion for consumer integration, consumers are now seen as critical stakeholders and valued resources in the policy process.

Consumers also have become advocates in the communities where they live and work. Advocacy enables consumer groups to shape policy at the local level, where a direct impact can be felt. At the local level, advocacy strives to improve access to, or quality of, needed services and to counter employment and housing discrimination. It can also be helpful in mobilizing resources to build and sustain programs. The National Mental Health Association (NMHA, available at <http://www.nmha.org>), comprising more than 340 affiliates nationwide, works with and supports the efforts of consumers to achieve advocacy goals.

Family Self-Help

Family members of people with severe mental illnesses also encounter ignorance and stigma. Stigma translates into avoiding or blaming family members (Phelan et al., 1998; Wahl & Harman, 1989). Families also are under a great deal of stress associated with care giving and obtaining resources for their mentally ill members.

Families—especially parents, siblings, adult children, and spouses—often provide housing, food, transportation, encouragement, and practical assistance. At the same time, schizophrenia and other mental disorders strain family ties. Symptoms of mental disorders may be disruptive and troubling, especially when they flare up. Even when there are no problems, living together can be stressful—interpersonally, socially, and economically. Parents and their adult children often perceive mental disorders and treatment differently, sometimes disagreeing about the best course of action.

Consequently, families too have created support organizations. Some of these are professionally based and facilitated, often as part of a clinic or other treatment program. Others are peer run in the self-help model. Similar to self-help among people with mental illnesses, family self-help can range from small

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supportive groups to large organizations. The National Alliance for the Mentally Ill (NAMI) is the largest such organization. Founded in 1979 in Wisconsin, NAMI now has 208,000 members nationally. It has more than 1,200 local self-help groups (affiliates) across all 50 states (see <http://www.nami.org>). While still growing, its members include only a small percentage of the family members of people with mental illnesses in the country (Monking, 1994; Heller et al., 1997a).

Family members primarily attend self-help and support groups to receive emotional support and accurate information about mental illness and mental health services (Heller et al., 1997a, 1997b). Participation often leads to better quality of life for the attending family members and also indirectly benefits the member diagnosed as mentally ill (Wahl & Harman, 1989; Monking, 1994). Family self-help groups can result in better communication and interaction among family members (Heller et al., 1997b).

Family Advocacy

In addition to providing each other with mutual support, families often devote time, energy, and resources for advocacy to improve services and opportunities for their family members with mental disorders. Similar to consumer advocacy, family advocacy on a local level might include organizing to improve local mental health services, or to redress grievances with service providers. On the national level, consumer groups work to influence legislation and to support research and education initiatives (Wahl & Harman, 1989). Through their advocacy, families have been quite effective in raising their concerns and perspectives to service providers, legislators, and the public.

Human Services

The clinical symptoms of schizophrenia and other mental disorders are often disruptive and distressing. Their consequences are no less severe—truncated education, unemployment, social isolation, and exclusion from community participation. Facing multiple life stressors, all severe, with a minimum of resources, people with severe mental illnesses often

need a variety of supportive services. Paramount among these are housing, employment and income assistance, and health benefits. Consumers have reported their major needs to include adequate income, meaningful employment, decent and affordable housing, quality health care, and education to increase skills (Ball & Havassy, 1984; Rosnow & Rucker, 1985; Lynch & Kruzich, 1986).

Housing

Housing ranks as a priority concern of individuals with serious mental illness. Locating affordable, decent, safe housing is often difficult, and out of financial reach. Stigma and discrimination also restrict consumer access to housing. Despite legislation such as the Fair Housing Act, allegations of housing discrimination based on psychiatric disabilities are highly prevalent (U.S. Department of Education, 1998). Landlords and public housing programs are often unwilling to accept tenants with severe mental disorders. In a survey of parents of mentally ill adults, the dearth of decent and affordable housing was a direct barrier to the person moving out of the family home, even when all parties wanted it (Hatfield, 1992).

The actual proportion of people with severe mental illnesses who lack affordable and decent housing has not been assessed directly. Yet indirect assessments point to a serious problem. In 1994, the U.S. Department of Housing and Urban Development (HUD) reported that almost half of all very low-income disabled residents—including persons with serious mental illness—have “worst case” needs for housing assistance. Furthermore, it was reported that the majority of these persons often live in the most severely inadequate housing (U.S. Department of Housing and Urban Development, 1994; U.S. Department of Education, 1998). It is estimated that up to one in three individuals who experience homelessness has a mental illness (Federal Interagency Task Force on Homelessness and Mental Illness, 1992).

The housing preferences of people with schizophrenia and other serious mental disorders are clear: these individuals strongly desire their own decent living quarters where they have control over who lives

with them and how decisions are made (Owen et al., 1996; Schutt & Goldfinger, 1996; Sohng, 1996). In an analysis of 26 consumer preference surveys, Tanzman (1993) found that at least 59 percent of those surveyed wanted independent living in a house or apartment. They also preferred to live alone (or with a spouse or partner), yet not with other people with mental disorders. Most also preferred access to mental health and rehabilitation services to support them where they were living.

When deinstitutionalization led to the need for more community housing, the residential programs that were developed replicated institutional programs (Carling, 1989). Although residential programs varied in the degree of oversight and services, they generally proved to be ineffective in meeting consumers' needs. Moreover, living in such programs added to stigma. Because of these shortfalls, greater emphasis has been placed on conventional housing supplemented by appropriate assistance tailored to individual need (Srebnik et al., 1995). This new concept, called supported housing, moves away from "placing" clients, grouping clients by disability, staff monopolizing decisionmaking, and use of transitional settings and standardized levels of service (Carling, 1989; Lehman & Newman, 1996). Instead, supported housing focuses on consumers having a permanent home that is integrated socially, is self-chosen, and encourages empowerment and skills development. The services and supports offered are individualized, flexible, and responsive to changing consumer needs. Thus, instead of fitting a person into a housing program "slot," consumers choose their housing, where they receive support services. The level of support is expected to fluctuate over time. With residents living in conventional housing, some of the stigma attached to group homes and residential treatment programs is avoided.

Although there are no randomized clinical trials to support the effectiveness of the supported housing approach, consumer advocacy and changes in clinical practice affirm the shift to supported housing. In a quasi-experimental study, an evaluation of the Robert Wood Johnson Foundation Program on Chronic Mental

Illness demonstrated the feasibility and modest benefits of the supported housing approach using rental subsidies from HUD (Newman et al., 1994). Consumers experienced better mental health and more self-determination when they lived in adequate housing (Nelson et al., 1998). For example, one study found that personal empowerment and functioning were enhanced, and hospitalization reduced, after 5 months in a supported housing program (McCarthy & Nelson, 1991). Also, resident control over decisions was directly related to satisfaction and empowerment (Seilheimer & Doyal, 1996). Similarly, another study found that having greater choice in housing was associated with greater happiness and life satisfaction (Srebnik et al., 1995).

Despite these findings, serious housing problems persist for people with schizophrenia and other mental disorders. Most such individuals are poor and thereby face very limited housing options.

Income, Education, and Employment

People with severe mental illnesses tend to be poor (Polak & Warner, 1996). Although the reasons are not understood, poverty is a risk factor for some mental disorders, as well as a predictor of poor long-term outcome among people already diagnosed (Cohen, 1993; Rabins et al., 1996; Saraceno & Barbui, 1997). People with serious mental illnesses often become dependent on public assistance shortly after their initial hospitalization (Ho et al., 1997). They rely on government disability-income programs, rent subsidies (Loyd & Tsuang, 1985; Polak & Warner, 1996; Ho et al., 1997), and informal sources of economic support (e.g., living with parents). The unemployment rate among adults with serious and persistent mental disorders hovers at 90 percent (National Institute on Disability and Rehabilitation Research, 1992).

Conversely, adequate standards of living and employment are associated with better clinical outcomes and quality of life (Cohen, 1993; Bell & Lysaker, 1997). In a randomized trial of consumers assigned to paid versus unpaid work, paid employment was found to reduce symptoms of schizophrenia (Bell et al., 1996). Moreover, employer accommodations for

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those with psychiatric disabilities appear to be inexpensive. The most frequently requested accommodations focus on orientation and training of supervisors, provision of onsite support, and adaptive work schedules. Such accommodations rarely result in significant cost to the employer (Mancuso, 1990; Fabian et al., 1993).

While newer vocational rehabilitation and employment initiatives strive to remedy persistently high levels of unemployment, most consumers find themselves unable to work consistently or at all. This is due not only to active symptoms but also to profound interruptions of education and employment caused by symptom onset and exacerbations, stigma and discrimination, lack of higher education programs for this population, and low-paying menial jobs.

When the onset of mental health problems begins during school-age years, educational systems are often ill prepared. Several studies have identified educational deficits in their clientele, who function in reading and math at a level far below their achieved grades in school (Cook et al., 1987; Cook & Solomon, 1993). Supported education models can provide assistance to consumers with their education (Cook & Solomon, 1993; Hoffman & Mastrianni, 1993; Ryglewicz & Glynn, 1993). One example is Consumers and Alliances United for Supported Education, a consumer-operated program in Quincy, Massachusetts, that provides a wide range of services to encourage individuals with psychiatric disabilities to enter or reenter college or technical school programs. Services include academic and career counseling, assistance with finding financial aid, study skills, stress control, tutoring/coaching, and assistance with crisis while hospitalized (CMHS, 1996).

Consumers lack control over their financial affairs when benefit checks are given directly to care providers for the person's housing and other expenses, or to a legally appointed representative payee (if the person has been deemed unable to manage his/her own finances) (Conrad et al., 1998). Those consumers who manage their own finances usually face such modest monthly budgets that there is no room for error. Funds frequently are depleted before the end of the month.

Furthermore, disability payments are sometimes reduced or discontinued when a recipient is working. Since employment is rarely consistent, they need to resume disability benefits. Yet, once they are canceled, government disability benefits can be cumbersome to restart. The Social Security Administration has developed new measures to facilitate reactivation of benefits for individuals who return to work, but they are not yet widely disseminated. In some ways the requirements of Social Security disability benefits and other such programs often act as disincentives to the pursuit of employment (Polak & Warner, 1996; Priebe et al., 1998).

Some people with serious mental illnesses have adequate income or financial assistance (Ware & Goldfinger, 1997). Some have affluent families who can subsidize their expenses. Others collect pensions because they were not disabled by their illness until after they had a substantial work history. Finally, some have found well-paying positions through a formal rehabilitation program, a community-based educational or vocational training program, or a supportive employer.

Health Coverage

Health coverage goes hand in hand with housing and income in determining standards of living for people with serious psychiatric disabilities. Due to their low incomes and the high cost of psychiatric and other health services, most people with schizophrenia and other forms of severe and persistent mental disorders rely on Medicare, Medicaid, and other government programs to cover their therapeutic services, medications, and other health care. When reductions or loss of these benefits curtail access to needed medication or services, clients' health suffers and their use of more expensive emergency services increases (Soumerai et al., 1994). Even when they have access to health insurance coverage, individuals with a mental disorder encounter barriers to procuring that insurance and in receiving general medical care (Druss & Rosenheck 1998).

Integrating Service Systems

Integrating the range of services needed by individuals with severe and persistent mental disorders has been a vexing problem for decades. The General Accounting Office (1977) criticized the Federal community mental health centers for their failure to meet the multiple needs of individuals with chronic mental illness. The Federal response was to establish a Community Support Program to provide resources and technical assistance to communities to help them in formulating community support systems to integrate the various services provided by fragmented human services agencies (Turner & TenHoor, 1978; Tessler & Goldman, 1982). The limitations of a community support program in dealing with severe and persistent mental illness in major cities, particularly those with high rates of homelessness, prompted the Robert Wood Johnson Foundation to partner with HUD to create the Program on Chronic Mental Illness (Aiken et al., 1986). This program promoted the concept of local mental health authorities as the agencies responsible for integrating all services for individuals with chronic mental illness, including housing opportunities (Shore & Cohen, 1990, 1994). The Robert Wood Johnson Foundation Program on Chronic Mental Illness was initiated in late 1986 and evaluated over a 6-year period (Goldman et al., 1990a, 1990b, 1994a, 1994b).

The evaluation determined that local mental health authorities were established or strengthened in almost all of the nine cities, resulting in measurable increases in organizational centralization and reduced fragmentation of services (Morrissey et al., 1994). Case management services also were expanded, producing greater continuity of care and reductions in family burden (Lehman et al., 1994; Shern et al., 1994; Tessler et al., 1994). Client outcomes, including social functioning and quality of life measures, improved during the demonstration (Lehman et al., 1994; Shern et al., 1994). Yet the time course of most clients' improvement did not coincide with improvements in system integration. This suggested that their improvement could not be attributed to system integration. For a subset of clients, improved client outcomes were due to the benefits of special combined

housing and support services. Yet, even for this subset, improvements were related, but not directly attributable, to systems integration (Newman et al., 1994).

Evaluators concluded that system integration and traditional case management alone probably were not sufficient to produce optimal social and clinical outcomes (Goldman et al., 1994b; Lehman et al., 1994). They speculated that the availability of rental subsidies and supports or more intensive and higher quality case management services—such as those offered in assertive community treatment—were essential (Ridgely et al., 1996). This set of findings, coincident with the release of the report of the Federal Interagency Task Force on Homelessness and Mental Illness (1992), *Outcasts on Main Street*, prompted the development of another demonstration program.

Access to Community Care and Effective Services and Supports was launched by the Federal Center for Mental Health Services in 1993 (Randolph et al., 1997). Still in the midst of its evaluation, preliminary findings sustain the benefits of providing assertive community treatment to obtain good clinical and social outcomes. They support the association of better system integration with higher rates of moving individuals with severe mental illness from homelessness into independent housing (Rosenheck et al., 1998a). It remains to be seen, however, whether the improvements in system integration observed over time are associated with improvements in consumers' clinical and social outcomes.

Integrating service systems remains a challenge to mental health and related human service agencies. Its benefits for accountability and centralization of authority have been established. Its impact on individuals with severe and persistent mental illness may be limited by the lack of available high-quality services and mainstream welfare resources, reflecting the gap between what can be done and what is available (Goldman, 1998a).

Conclusions

1. As individuals move into adulthood, developmental goals focus on productivity and intimacy including pursuit of education, work, leisure, creativity, and personal relationships. Good mental health enables individuals to cope with adversity while pursuing these goals.
2. Untreated, mental disorders can lead to lost productivity, unsuccessful relationships, and significant distress and dysfunction. Mental illness in adults can have a significant and continuing effect on children in their care.
3. Stressful life events or the manifestation of mental illness can disrupt the balance adults seek in life and result in distress and dysfunction. Severe or life-threatening trauma experienced either in childhood or adulthood can further provoke emotional and behavioral reactions that jeopardize mental health.
4. Research has improved our understanding of mental disorders in the adult stage of the life cycle. Anxiety, depression, and schizophrenia, particularly, present special problems in this age group. Anxiety and depression contribute to the high rates of suicide in this population. Schizophrenia is the most persistently disabling condition, especially for young adults, in spite of recovery of function by some individuals in mid to late life.
5. Research has contributed to our ability to recognize, diagnose, and treat each of these conditions effectively in terms of symptom control and behavior management. Medication and other therapies can be independent, combined, or sequenced depending on the individual's diagnosis and personal preference.
6. A new recovery perspective is supported by evidence on rehabilitation and treatment as well as by the personal experiences of consumers.
7. Certain common events of midlife (e.g., divorce or other stressful life events) create mental health problems (not necessarily disorders) that may be addressed through a range of interventions.
8. Care and treatment in the real world of practice do not conform to what research determines as best. For many reasons, at times care is inadequate but there are models for improving treatment.
9. Substance abuse is a major co-occurring problem for adults with mental disorders. Evidence supports combined treatment, although there are substantial gaps between what research recommends and what typically is available in communities.
10. Several special problems in care and treatment of adults have been recognized, beyond traditional mainstream mental health concerns, including racial and ethnic differences, lack of consumer involvement, and the consequences of disability and poverty.
11. Barriers of access exist in the organization and financing of services for adults. There are specific problems with Medicare, Medicaid, income supports, housing, and managed care.

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